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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Agency for Healthcare Research and Quality

Request for Measures and Domains to Use in Development of a standardized instrument for use in public reporting of family experience of pediatric inpatient care

AGENCY: Agency for Healthcare Research and Quality (AHRQ), HHS.

ACTION: Notice of Request for measures and domains.

SUMMARY: Section 401(a) of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), Pub. L. 111-3, amended the Social Security Act (the Act) to enact section 1139A (42 U.S.C. 1320b-9a). Section 1139A (b) charged the Department of Health and Human Services with improving pediatric health care quality measures. The Agency for Healthcare Research and Quality (AHRQ) is soliciting the submission of instruments or domains (for example, key concepts) measuring aspects of families' experience with the quality of inpatient medical and surgical hospital care from all researchers, vendors, hospitals, stakeholders, and other interested parties. The survey development team of Children's Hospital Boston Center of Excellence for Pediatric Quality Measurement (CEPQM), is one of the CHIPRA Pediatric Quality Measures Program (PQMP) Centers of Excellence, which were created pursuant to an interagency agreement between the Centers for Medicare & Medicaid Services (CMS) and AHRQ, and are funded through cooperative agreement awards with AHRQ. AHRQ is interested in instruments and items through which families of pediatric patients assess the care their child receives during the child's inpatient stay. The goal is to develop a standardized instrument for use in the public reporting of family experience of pediatric inpatient care. The team developing this survey intends to submit it to the CAHPS Consortium to request use of the CAHPS trademark. The survey will be developed in accordance with CAHPS Survey Design Principles and will develop implementation instructions based on those for CAHPS instruments (<https://www.cahps.AHRQ.gov/About-CAHPS/Principles.aspx>.) All CAHPS surveys are available to users free of charge and are published on the AHRQ website.

DATES: Please submit materials [Insert date 30 DAYS OF PUBLICATION OF THIS NOTICE]. AHRQ will not respond to individual submissions, but will consider all suggestions.

ADDRESSES: Electronic submissions are encouraged, preferably as an e-mail with an electronic file in a standard word processing format as an e-mail attachment. Submissions may also be in the form of a letter to:

Maushami DeSoto, MHA, Ph.D.
Staff Service Fellow, Office of Extramural Research, Education and Priority
Populations Agency for Healthcare Research and Quality
540 Gaither Rd
Rockville, MD 20850
Phone: 301-427-1546
Fax: 301-427-1238
E-mail: Maushami.DesotoAHRQ.hhs.gov

All submissions must include a written statement from the submitter that it will grant AHRQ the necessary rights to use, modify, and adapt the submitted instruments, items, and their documentation for the development of this survey and its dissemination for AHRQ purposes. In accordance with CHIPRA's charge to improve pediatric quality care measures, and consistent with AHRQ's mandate to disseminate research results, 42 U.S.C. § 299c-3, AHRQ purposes include public disclosure and dissemination (e.g., on the AHRQ website) of AHRQ products and the results of AHRQ-sponsored research and activities. The written statement must be signed by an individual authorized to act for any holder of copyright and/or data rights on each submitted measure or instrument. The authority of the signatory to provide such authorization should be described in the letter. Submitters must attach a proposed license granting all of the above-referenced rights, including the following terms:

- a worldwide, royalty-free, nonexclusive, irrevocable license to AHRQ and those acting on its behalf to reproduce, prepare derivative works of, and otherwise use the submitted materials for the development of AHRQ products, including a standardized instrument for use in the public reporting of family experience of pediatric inpatient care; and
- the right of AHRQ and those acting on its behalf to publicly disseminate, in any media (including AHRQ's website), any derivative works that AHRQ or those acting on its behalf develops based on the submitted materials.

Submission Guidelines

When submitting instruments, please include, to the extent that it is available:

- Name of the instrument;
- Copies of the full instrument, in all languages available;
- Domains or key concepts included in the instrument;
- Instrument reliability (internal consistency, test-retest, etc) and validity (content, construct, criterion-related);
- Results of cognitive testing;
- Results of field-testing;
- Current use of the instrument (who is using it, what it is being used for, how instrument findings are reported, and by whom the findings are used); and,
- Relevant peer-reviewed journal articles or full citations.

When submitting domains, please include, to the extent available:

- Detailed descriptions of question domain and specific purpose;
- Sample questions, in all languages available; and,
- Relevant peer-reviewed journal articles or full citations. For all submissions, please also include:
- A brief cover letter summarizing the information requested above for submitted instruments and domains, respectively;
- Complete information about the person submitting the material, including:
 - a) Name;
 - b) Title;
 - c) Organization;
 - d) Mailing address;
 - e) Telephone number;
 - f) E-mail address; and,
 - g) The written statement granting AHRQ the necessary rights to use, modify, and adapt the submitted instruments, items, and their supporting documentation for the development of the survey and its dissemination for AHRQ purposes, as described above.

FOR FURTHER INFORMATION CONTACT: Maushami DeSoto, MHA, Ph.D.

SUPPLEMENTARY INFORMATION:

Section 401(a) of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), Pub. L. 111-3, amended the Social Security Act (the Act) to enact section 1139A (42 U.S.C. 1320b-9a). Since the law was passed, the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare & Medicaid Services (CMS) have been working together to implement selected provisions of the legislation related to children's health care quality. Section 1139A(b) of the Act charged the Department of Health and Human Services with improving pediatric health care quality measures. To implement the law, AHRQ and CMS have established the CHIPRA Pediatric Quality Measures Program (PQMP), which is designed to enhance select pediatric quality measures and develop new measures as needed.

The Children's Hospital Boston Center of Excellence for Pediatric Quality Measurement (CEPQM) is one of seven CHIPRA PQMP Centers of Excellence, which were created pursuant to an interagency agreement between CMS and AHRQ and funded through cooperative agreement awards with AHRQ. CEPQM has been assigned to develop a family experience of pediatric inpatient care measure to be

considered as a standardized instrument for publicly reporting pediatric inpatient hospital family experiences voluntarily by State Medicaid and CHIP programs and to be used by providers, consumers, other public and private purchasers, and others. The team developing this survey intends to submit it to the CAHPS Consortium to request use of the CAHPS trademark.

Existing instruments or domains submitted should capture the family's experience of hospital or related care (for example, preparation for discharge or care coordination). The survey development team is looking for items for which families of pediatric inpatients are generally the best or only judge; for example., the family can best say if the provider spent sufficient time with them or explained things in ways they could understand. Existing instruments that have been tested should have a high degree of reliability and validity; and evidence of wide use will be helpful.

Dated: December 20, 2011

Carolyn M. Clancy,
AHRQ Director

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